Issues of Attrition in a Population Study of Traumatic Brain Injury (TBI) Followed to 3 Years Post-Trauma

Abstract

Objective:
The Tasmanian Neurotrauma Register (TNTR) began prospective data collection in December 2003 as part of a population based study of Traumatic Brain Injury (TBI) in Southern Tasmania. The overall research aim of the TNTR is to provide comprehensive assessment data on outcomes across a number of domains, including cognitive, psychological and medical. The aim of the present paper is to discuss the issues involved in following a population cohort of TBI patients over multiple time points – one month, three months, six months, twelve months, two years and three years post trauma.

Method:
A population sample of 947 individuals presenting with TBI at the Department of Emergency Medicine, Royal Hobart Hospital, participated. Data was collected on a range of demographic, clinical, cognitive and psychosocial variables up to three years post-injury. Attendance and attrition data were examined using a number of methods.

Results:
Participants with more severe TBI’s (measured using length of Post Traumatic Amnesia) showed higher retention rates in the study. Attendance was also examined looking at demographic variables including age and gender. Educational history and socioeconomic status are still under analysis.

Discussion:
The issue of attrition from large sample studies warrants further investigation to allow such studies to take into account the risk of biased findings from differential drop-out. Different methods of calculating attrition need to be addressed when investigating outcome after TBI, particularly given the characteristics of those at risk of sustaining brain injury.

A growing body of research has identified TBI as a global and silent epidemic due to the prevalence of TBI appearing to be greater than the reported incidence (Langlois et al 2005). This problem is exacerbated as the majority of TBI studies report a loss to follow up or attrition rate of one third to one half of their original participants (Corrigan et al 2003). The maintenance of participants within longitudinal TBI studies is costly and time consuming however, it is important this is maximised to reduce the risk of decreased generalisation and the introduction of bias into the final results (Risbel et al 1996). Identification of the characteristics of those whose survival in studies at risk is helpful in the planning of new studies and may be beneficial in clinical area as attrition rates from clinical programs may draw from the same population.
The initial aim of this paper was to compare our attrition rates with other studies, to monitor our own progress and examine any potential biases within our population. With the review of the current literature it became increasingly difficult to draw comparisons due to the differences in definition of mild traumatic brain injury (MTBI), levels of severity of TBI and methodologies for calculations of lost-to-follow-up rates, which are well documented (Carroll et al 2003). We then sought to look at the contrast between the attrition rates of the total population, broken down into levels of severity on a longitudinal basis and then cross-sectionally.

**Methods**

The Tasmanian Neurotrauma Register is a prospective population based study run by the University of Tasmania in conjunction with the Royal Hobart Hospital. Participants who have consented to the study are interviewed as close to the time of injury as possible and then seen at one month, three months, six months, twelve months, two years and three years post injury. Interviews are conducted on a face to face basis with post graduate psychology students and involve a battery of tests covering physical, social and cognitive domains. Each interview takes 60 – 90 minutes. There is no means of reimbursement or incentive for the participants but home visits were offered if people were unable to travel. The only exclusion factors for the study were anyone under the age of 16 and anyone with dementia.

**Participants**

The injuries sustained by participants were mostly related to transport, and they employment status of them is as follows:

*Injury mechanism:*
- Motor vehicle/transport 39%
- Assaults 27%
- Falls 19%
- Sport 7%
- Other 8%

*Employment status:*
- Employed 47%
- Students 13%
- Retired 11%
- Unemployed 10%
- Disability pensioner 5%
- Home duties 4%

The mean age of participants was 36.08 years (standard deviation = 17.69), and 35 percent of participants were female. Geographically the area covers Southern Tasmania which is the catchment for the Royal Hobart Hospital (tertiary referral centre for head injuries). Although this region caters for acute care services there is no specialised brain injury rehabilitation unit and follow up care is limited.
Calculations
Calculations of the attrition rate were made after the study had been running for three years. This was done looking at the total number of participants over this period as one complete population.

Table 1. Overall rates of attrition NTR

<table>
<thead>
<tr>
<th>Time Point</th>
<th>Percentage of response rate</th>
<th>Attrition rate</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 month</td>
<td>78%</td>
<td>22%</td>
</tr>
<tr>
<td>3 months</td>
<td>65%</td>
<td>35%</td>
</tr>
<tr>
<td>6 months</td>
<td>63%</td>
<td>37%</td>
</tr>
<tr>
<td>12 month</td>
<td>62%</td>
<td>38%</td>
</tr>
<tr>
<td>24 month</td>
<td>39%</td>
<td>61%</td>
</tr>
<tr>
<td>36 month</td>
<td>19%</td>
<td>81%</td>
</tr>
</tbody>
</table>

To attempt to identify the rise in attrition rate at the twenty-four month period it was decided examine the levels of severity of brain injury in the study and observe each level as a sub population. Level of severity was defined by length of Post Traumatic Amnesia (PTA).

Table 2. Severity of traumatic brain injury (based on Russell, 1977)

<table>
<thead>
<tr>
<th>Severity</th>
<th>Duration of PTA</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Very Mild</td>
<td>&lt;= 5 minutes</td>
<td>258</td>
<td>27</td>
</tr>
<tr>
<td>Mild</td>
<td>5 to 60 minutes</td>
<td>211</td>
<td>23</td>
</tr>
<tr>
<td>Moderate</td>
<td>1 to 24 hours</td>
<td>258</td>
<td>27</td>
</tr>
<tr>
<td>Severe</td>
<td>1 to 7 days</td>
<td>147</td>
<td>16</td>
</tr>
<tr>
<td>Very severe</td>
<td>1 to 4 weeks</td>
<td>51</td>
<td>5</td>
</tr>
<tr>
<td>Extremely severe</td>
<td>&gt; 4 weeks</td>
<td>22</td>
<td>2</td>
</tr>
</tbody>
</table>

Break down of level of severity within studied population in TNTR
Within Table 2 the number of participants can be seen at each level of severity. Fifty percent of participants fall into the mild and very mild category with the moderate category making up twenty seven percent and the remaining twenty three percent falling in to the severe to extremely severe category.
Table 3: Response rates as a percentage at each time point for various length of PTA in a longitudinal model

<table>
<thead>
<tr>
<th>PTA</th>
<th>Baseline</th>
<th>Day 28</th>
<th>Day 90</th>
<th>6 Months</th>
<th>12 Months</th>
<th>24 Months</th>
<th>36 Months</th>
</tr>
</thead>
<tbody>
<tr>
<td>0-5 mins</td>
<td>100</td>
<td>74</td>
<td>62</td>
<td>58</td>
<td>52</td>
<td>45</td>
<td>32</td>
</tr>
<tr>
<td>5-60 mins</td>
<td>100</td>
<td>74</td>
<td>68</td>
<td>56</td>
<td>53</td>
<td>41</td>
<td>29</td>
</tr>
<tr>
<td>1-24 hours</td>
<td>100</td>
<td>79</td>
<td>69</td>
<td>65</td>
<td>54</td>
<td>40</td>
<td>37</td>
</tr>
<tr>
<td>1-7 days</td>
<td>100</td>
<td>88</td>
<td>70</td>
<td>67</td>
<td>60</td>
<td>50</td>
<td>54</td>
</tr>
<tr>
<td>1-4 weeks</td>
<td>100</td>
<td>87</td>
<td>79</td>
<td>71</td>
<td>67</td>
<td>68</td>
<td>66</td>
</tr>
<tr>
<td>28+ days</td>
<td>100</td>
<td>100</td>
<td>87</td>
<td>86</td>
<td>86</td>
<td>83</td>
<td>66</td>
</tr>
</tbody>
</table>

When the population of TNTR was divided into severity groups, and calculations were done separately on each group at each time point a clearer picture emerged on the attrition rates from the study. If participants missed a follow up staff would attempt to follow them up at the next time point unless they had actively withdrawn from the study. Therefore it was possible that someone may have attended one time point, missed one then appeared at the next time point.

Table 3 demonstrates that participants with milder injuries are lost from the study earlier than those with moderate to severe injuries. The greatest level of attrition appears to occur after the twelve month period. The greater the level of severity the more responsive participants were to follow up.

If each time point is treated as an individual study such as cross-sectional time points the attrition rate is viewed differently. It becomes the percentage of people we were unable to contact at that particular time point. All those previously withdrawn prior to the time point in question were disregarded before the calculations made. The figures reflect the efforts made to contact those who had not formally withdrawn and the success of contact at this time.

Table 4: Percentage response rates at each time point for various levels of severity as a cross sectional model

<table>
<thead>
<tr>
<th>PTA</th>
<th>Baseline</th>
<th>Day 28</th>
<th>Day 90</th>
<th>6 Months</th>
<th>12 Months</th>
<th>24 Months</th>
<th>36 Months</th>
</tr>
</thead>
<tbody>
<tr>
<td>0-5 mins</td>
<td>100</td>
<td>74</td>
<td>68</td>
<td>71</td>
<td>70</td>
<td>75</td>
<td>55</td>
</tr>
<tr>
<td>5-60 mins</td>
<td>100</td>
<td>74</td>
<td>72</td>
<td>66</td>
<td>70</td>
<td>66</td>
<td>64</td>
</tr>
<tr>
<td>1-24 hrs</td>
<td>100</td>
<td>79</td>
<td>72</td>
<td>70</td>
<td>65</td>
<td>57</td>
<td>63</td>
</tr>
<tr>
<td>1-7 days</td>
<td>100</td>
<td>88</td>
<td>72</td>
<td>75</td>
<td>73</td>
<td>69</td>
<td>74</td>
</tr>
<tr>
<td>1-4 weeks</td>
<td>100</td>
<td>87</td>
<td>79</td>
<td>73</td>
<td>70</td>
<td>83</td>
<td>66</td>
</tr>
<tr>
<td>28+ days</td>
<td>100</td>
<td>100</td>
<td>86</td>
<td>90</td>
<td>90</td>
<td>91</td>
<td>100</td>
</tr>
</tbody>
</table>
As before with Table 3, Table 4 includes people who attended one time point but may have missed one or more previous time points. They remain eligible for contact and assessment until they formally withdrew from the study or missed three consecutive assessment dates. As a result there is not always a gradual decline in attendance as may be expected. The moderate and severe categories both show increases in attendances from the 2 year period to the 3 year period and within the severe category the assessment rate increased by 12% from the 12 month to two year period but fell again by 16% at the three year point. There were no changes in staffing levels or contact techniques that may attribute to this difference in attendance.

The associations of demographic and clinical variables with survival in the study were examined in a number of ways. Age, gender, education and PTA were investigated using Cox Regression analyses (Tabachinick and Fidell, 2001) form SPSS. Although gender was not identified as significantly influencing retention, age, education and PTA were all related to survival in the study at each of the follow-up points. Other characteristics of those that survive within the study are still under analysis.

Discussion

As discussed in the introduction the initial aim of this paper was to examine our own level of attrition, compare it with other studies and seek to anticipate any areas of potential bias that may be created by systematic loss to follow up. This proved difficult as the methodology differed between studies as did the definition of TBI and characteristics of the participants.

Observed studies did not span all levels of severity; were hospital based; the follow up periods were less frequent than TNTR and they covered different domains using predominately phone or mail follow up. Definition of severity also differed between studies making comparison challenging. (Jakola et al 2007, Stalnake 2007, Tomberg et al 2007, Stulemiejier et al 2006, Boake et al 2005, Kraus et al 2005, Van der Naalt et al 1999, Olver et al 1996.).

Attrition rates within the literature are usually documented at part of a broader study. Only one research group was found that devoted two articles to loss to follow up in TBI studies (Corrigan 2003, Corrigan 1997). These papers examined the possibilities of systematic bias due to attrition across three large data bases in the USA. There study samples were drawn from hospital admissions with a diagnosis of TBI and two of the three data bases had patients who had been admitted to specialised brain injury rehabilitation units. The participants were contacted by phone with follow up mail questionnaires in two of the centres and face to face interviews prioritised in the other.

At the one year time point the Suboptimal Outcome Study as described by Corrigan had an attrition rate of 42% and at the two year point this was 49%. The Traumatic Brain Injury Model System’s attrition rate at 1 year was 41% and then 45% at two years. The Colorado Traumatic Brain Injury Register experienced 42% attrition at one year. In the second year they did not attempt to contact patients they had been unable to contact in the first year and only contacted those who had previously participated. This reduced the number of patients that were eligible for contact and subsequently reduced their attrition rate to 15%.

Most studies in TBI focus on one or two levels of severity. Within the range of studies on MTBI to moderate TBI much work has been done to highlight the level of disability that may be experienced within this category of injury (Jakola et al 2007, Stalnake 2007, Stulemiejier et al 2006, Boake et al 2005, Kraus et al 2005, Van der Naalt et al 1999). As previously discussed the methodologies and definitions varied between these studies and the attrition rates are an observation of the work not a focus of the study. Stalnake (2007) reported an attrition rate of only 20% with a three year follow up of social support in MTBI and outlines in the latter part of the paper this may be through the demographics and the geographic location.
The influences of demographic factors in TNTR attrition rates are still under analysis. Another area of contrast in this study with TNTR is there was only one follow up point at the three year post injury point and participants were sent questionnaires. No face to face interviews were attempted. Other studies fluctuated between 35% to 55% attrition rate at the six month period (Kraus 2005, Boake 2005 and Stulemeijer 2006).

Studies that have focused on moderate to severe injuries have focused on fixed extensive time points such as follow up at two or five years (Olver et al 1996, Tomberg et al 2007). These studies have reported a non response rate of 52% at two years and 80% at five years. This highlights the difficulty of following up the TBI population on a longitudinal basis in a research perspective.

Pickelsimer et al (2006) cover all levels of severity in their population based study and followed up at one, two and three years. They reported 43% attrition across the whole study but did not report on individual levels of severity.

The geographical location of TNTR does not have a specialised brain injury unit although it is linked to a tertiary referral centre that manages neurosurgery on a state-wide basis. The rehabilitation of brain injury occurs within mainstream rehabilitation but there is little coordination around the follow up care for all severities of TBI. This may or may not have an effect on the ability of TNTR to follow participants as some may view it as providing them with an unintentional therapeutic consultation that was otherwise unavailable in the community. Equally it may have been difficult to identify the TBI population due to the lack of coordinated services.

As TNTR was an intensive program for participants the length of time asked of them and the frequency of attendance in the first year may have caused participant fatigue and been attributable to attrition. Conversely the attrition of the mild and moderate TBI population rises from the low forties to the mid fifty percent between the one and two year mark it may have held attrition rates steadier if and eighteen month time point had been included.

Limitations

When identifying participant’s employment profile it would have been more useful to categorise peoples working profiles into professional, semi professional, tradespeople and unskilled labour.

Conclusions

Difficulty occurs when trying to compare attrition rates between studies and therefore benchmark figures. The differences in methodology may present some advantages as some participants may respond better to a one – two year follow (Corrigan 2003) where face to face interviewing is not required and routine brain injury units and clinical follow up is available. A more intense research program with multiple assessment points over three years also has its advantages and disadvantages.

The experience of the TNTR is that severity of injury is a factor in the survival of participants within longitudinal studies as is level of education and age. More work needs to be done to correlate this with clinical programs for people with brain injury so early identification of those who are at risk of not participating in therapy can be made and programs modified to assist in retaining them.
References


Langlois JA, Marr A, Mitchko J, Johnson RL. Tracking the silent epidemic and educating the public. Journal of Head Trauma Rehabilitation 2005;20:196-204.


